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ABSTRACT

A survey of parents (n=384) of children attending early intervention programs for developmentally delayed preschoolers and infants in San Diego (California) examined what proportion of identified developmentally delayed young children also have special health care needs, what the nature of these needs are, and whether these health needs obstruct child daycare placement. Analysis of responses indicated that over one third of the children had a special health care need. Mobility limitation, recurrent seizures, use of a gastric tube, and severe asthma were the most common problems. Thirty-five percent of all parents reported that the lack of child day care was keeping a family member from active employment. Although parents with children having a special health care need were more likely to perceive their child's disability as a barrier to childcare placement, success with childcare placement was not different from those whose special need was not health related. Childcare placement was at 34 percent, compared to national averages of 50 percent to 62 percent for young children without special needs. Recommendations are offered to schools concerning their role in providing technical support to daycare programs. (Contains 10 references.) (DB)

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# CHILDREN WITH SPECIAL HEALTH CARE NEEDS IN EARLY INTERVENTION PROGRAMS: DESIRE FOR CHILD DAYCARE

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## ABSTRACT

Early intervention programs have brought young children with many special needs away from exclusive parental supervision and into community settings. We used early intervention programs to survey parents about the nature of their children's disabilities and about their need for child daycare services. Over one third of these children had a special health care need. Although these parents were more likely to perceive their child's disability as a barrier to childcare placement, success with childcare placement was not different from those whose special need was not health related. Over one third of all parents surveyed said that the inability to find childcare was keeping a family member from working. Childcare placement was at 34%, compared to national averages of 50% to 62% for young children with regular needs.



Key Words: chronic illness, children, handicap, daycare center, special needs

## INTRODUCTION

Large numbers of infants and young children with special health care needs are cared for outside the home; this is likely a result of two phenomena. One is that a greater percentage of mothers are employed outside of the home in the general population than in previous generations (Dawson & Cain, 1990). The other is that public funding for early intervention for children is bringing children with special educational needs out of exclusive parental care and into the community for a few hours every week. Many of these children may have special health care needs, too. Their parents and their early intervention professionals are recognizing that these children can be cared for outside the home, and they seek child daycare that is safe and nurturing. Parental needs for child daycare may receive even more attention when Individualized Family Service Plans are routinely prepared for these families, as required by Public Law 99-457.

There is less child daycare availability for children with "special needs" than for other children (Walker, 1991). The availability of child daycare for the sub-population of children with special health care needs is unknown. The National Health and Safety Performance Standards, developed by the American Public Health Association and the American Academy of Pediatrics (1992), outlines standards of care for programs that enroll children with special needs. One guideline is that health and child development professionals participate in developing curricula which maintain a safe environment and meet specific needs of each child. Information about the nature of the special needs population attending child daycare is required in order to prepare health professionals to provide education and consultation for child daycare providers.

The aims of this study were: to determine what proportion of identified developmentally-delayed, preschool-age children (0 to 5 years) also have special health care needs; to determine the nature of these needs; and, to assess if health needs further obstruct child daycare placement.

## METHODS

Subjects

The population consisted of 678 children attending special programs for developmentally-delayed preschoolers and infants (ages 0 to 5 years) enrolled in 31 San Diego schools. Admission to these programs was based on either a documented developmental delay at least 50% below the chronological age for social-emotional, cognitive, language, or motor development, or a delay of at least 25% below chronological age for two developmental parameters. Children ages 3 years and older were guaranteed placement if they qualified for the program, but approximately 31% of eligible children under age 3 who applied for services were on waiting lists. Priority of service on the waiting list was based on application date, not severity of the developmental delay. The number of children in the community who were eligible for early intervention services but were either not identified or were discouraged from applying because of the long waiting list is unknown. There were 260 children under age 3, and 418 between ages 3 and 5.

Teachers were given English and Spanish questionnaires to send home with each child. Non-respondents were reminded by the teacher at least once to respond. Of the 678 subjects, a total of 384 completed questionnaires were received, for a response rate of 57%.

Questionnaire

The questions elicited information on the nature of the child's special needs, the equipment the child needed in school, the parents' desire for child daycare, their success in finding child daycare, and perceived reasons for lack of success. Questions were formatted for multiple-choice responses, with additional space for more elaborate responses.

To assess the validity of parents' responses to questionnaire items, one of the most subjective questionnaire items--the nature of a child's disability--was also asked of teachers in a separate survey. One teacher in each classroom described the total number of children in the class for each of the 14 descriptions for disabilities that were on the parental questionnaire. The 14 listed disabilities (aside from the option of choosing "other") were: developmental delay, language delay/disorder, emotional/behavioral problem, vision impairment, recurrent seizures, severe asthma, medical condition requiring trained care, mental retardation, chronic infectious disease, movement limitation, hearing impairment, chest disease, kidney disease, and diabetes. There were no significant differences in the prevalence of teachers' responses for these disabilities from those of parents, excepting for two non-medical disabilities. Teachers were more likely to describe the children as "developmentally delayed" ($p < 0.001$) and "mentally retarded" ($p < 0.01$) than were parents.

Statistical Analysis

All analyses were conducted using the SPSS-X statistical package. The frequency of each response was calculated. To test differences for child daycare responses between children with different handicapping conditions, chi square tests were used.

## RESULTS

### Children with Special Health Care Needs

If a parent responded that their child had a current problem with recurrent seizures, severe asthma, a chronic infectious disease, chest disease, kidney disease, diabetes, or another condition that "required trained care," or if the child required use of a gastric feeding tube or tracheostomy, then that child was categorized as having a medical need. Chronic infectious diseases were included in this definition, despite the minimal amount of additional attention these children require, because stigmata associated with HIV, Hepatitis B and CMV viruses require that staff receive some specialized education (Wetterau & Stegelin, 1991). Children with limitations of movement but without special equipment and children with either visual or hearing handicaps were not included in our definition of physical handicap.

Of all respondents, 105 (27%) had a child with one or more of these medical needs. Recurrent seizures (12% of total), use of a gastric tube (5%), and severe asthma (4%) were the three single-most common reasons for this categorization. Children with each of the other medical conditions listed did not constitute more than 2% of the total population per condition. Of the total population, 78 (20%) responded that his or her child had a limitation of movement and used a wheel chair, had an orthotic, a brace or used a walker. Of the total population, 37% had either a medical or physical handicap or both and are defined hereon as children with special health care needs.

### Child Daycare

Of the study's total population of parents (all of whose children were receiving special education services), 132 (34%) looked for and successfully found child daycare, 125 (35%) said that the lack of child daycare was keeping a family member from active employment, and 93 (24%) responded that they would not take daycare if it were available. Parents with children having a special health care need were more likely to respond that their difficulty with finding child daycare was because providers were unwilling to care for their child's handicap ($p < 0.0001$) but rate of enrollment did not differ. Parents could also identify other barriers to obtaining daycare: high cost (22%), transportation (12%), and "other" (7%). These responses were the same among parents of children with or without special health care needs.

Of the 132 using childcare, 7% used center-based care, 34% used family daycare, 36% used a relative or a friend's home, and 45% had a babysitter at home.

## DISCUSSION

Over one third of infants and young children in special education programs in our urban school districts have special health care needs that would likely necessitate training for educators and daycare providers. More restrictive eligibility criteria for early intervention would be expected to increase or decrease the proportion of children with special health care needs. However, in this regard San Diego is similar to programs in other locations. The proportion of children with a special health care need (37%) is relatively high when one considers that only 2% of children in the age range of 0 to 21 years in special education programs have either an orthopedic or health impairment (National Center for Educational Statistics, 1991). National data show that of all children below age 5, 4.6% have a limitation of activity due to a chronic condition

(Reis & Brown, 1991). A prevalence rate of 37% in our population indicates that children with special health care needs are highly concentrated in early intervention programs.

Children who have the most severe and unstable disabilities and those who are dependent on medical technology and procedures require childcare staff with health training and/or services directly from health professionals. School districts and centers for "medically-fragile" children have found ways to provide this care (Palfrey, Haynie, Porter, Bierle, & Lowcock, 1992; Walker, 1991). Less demanding but serious disabilities, such as recurrent seizures, asthma, NG-tubes and special ambulatory equipment requirements, are more common in this population and are more likely to be easily handled in a childcare setting. Optimal safety for these children requires that childcare staff have more established and comprehensive communication with medical professionals than most have currently (Morse, 1990). Potential and existing models of care for children with special health care needs in early intervention programs must be evaluated, compared, and ultimately adapted to suit smaller programs.

It is logical that parents of children with special needs have similar pressures to acquiring childcare as other parents (Fewell, 1986). Some may have the financial option of foregoing their careers and employment (and choose to do so), as indicated by 24% of our sample who would not choose child daycare, if available. Only 32% of children in this study are in regular childcare--less than the 50% to 62% of all regular children in this age group who are enrolled in childcare, based on national statistics (Dawson & Cain, 1990).

Parents of children with special health care needs perceived more difficulty finding daycare because of their child's handicap, yet their success rate did not differ from parents whose children

have non-health related special needs. Berk and Berk (1982) found that although many preschools and daycare centers were willing to take in handicapped children, very few would accept them if the handicap was non-ambulation. The absence of difference between successful childcare placement among developmentally-delayed children with or without special health care needs in our study is not compatible with these previous findings. It may be that the effort expended in finding childcare is greater amongst parents of children with special health care needs, despite the same rate of success. Alternately, these parents may incorrectly perceive greater difficulty. This area requires further study.

Recommendations

Early childhood intervention programs are excellent places to educate parents of children with special health care needs about child daycare. Desire for child daycare services should be investigated by school staff. Early intervention programs operate through school districts and they typically have a health infrastructure to care for special health needs. Parents perceive special health needs to be a barrier to daycare availability. Consideration should be given to projects that test the feasibility for early intervention programs to provide technical and staff support to childcare programs in their neighborhoods. With this support, special health needs would no longer be barriers to participation in childcare programs that operate outside of the school district but collaborate with these districts.

Families' desire for child daycare services should be routinely considered and included in Individualized Family Services Plans (IFSPs). Specifics of their child's health needs that pertain to child daycare placement also need to be reviewed. Changes in the medical profession need to

occur so that it becomes common medical practice to take a history of families' child daycare needs.

Physicians also need to set up their offices so that ongoing communication with child daycare settings is facilitated. This would provide needed technical support to childcare settings.

These changes towards better collaboration and communication in three child-oriented professions (childcare, education, and health) would be reassuring to parents who currently must deal with each sector separately. Three-way communication will go a long way towards providing a safety net for children with special needs without incurring large new expenses.

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